Introduction
Consumer Direction in Long-Term Care

By Robyn I. Stone, guest editor

Over the past decade, researchers and policy makers have begun to pay increasing attention to consumer direction in long-term care. A number of factors, including aggressive advocacy on the part of younger people with disabilities, a growing consumer movement in health and long-term care, concerns about the costs of long-term-care services, and the recent shortage of front-line workers, have contributed to this heightened interest in consumer direction.

Opportunities, challenges, and limitations of this increasingly popular—and still controversial—approach.

I have had a long-standing interest in consumer direction as a researcher and policy maker responsible for aging and long-term-care policy in the U.S. Department of Health and Human Services. I was, therefore, delighted when the *Generations* editorial board asked me to serve as guest editor for a special issue on this topic. The expert contributors to this issue reflect the broad range of policy, practice, and research perspectives that are critical to our understanding of how consumer direction in long-term care evolved, the opportunities, challenges, and limitations of this approach, and future directions for the financing and delivery of long-term care.

Defining Consumer Direction

As policy makers begin to explore the potential and pitfalls of consumer direction in long-term care, it is critical to provide a clear definition of the concept and to identify the parameters of this approach. Consumer direction in long-term care starts with the premise that individuals with long-term-care needs should be empowered to make decisions about the care they receive, including having primary control over the nature of the services and who, when, and how the services are delivered. Consumer direction also assumes that long-term care is predominantly nonmedical, focused on primarily low-tech services and supports that allow individuals with disabilities to function as independently as possible. Thus, the consumer should not be forced to rely on professionals to make key decisions about care and to be "managed" by a formal system.

Consumer direction is not one strategy. It reflects a continuum of approaches based on

the level of decision making, control, and autonomy allowed in a particular situation. The cash model is at one end of the consumer-direction continuum. This approach assumes that people know what they need and how to purchase it. Cash benefits tied to level of need or some other criterion provide the long-term-care consumer with the greatest flexibility in using resources to meet particular needs. The consumer decides how to best use the dollars, including purchasing services from a formal vendor, hiring a next-door neighbor to help with activities of daily living, purchasing some type of assistive technology to enhance independence, or modifying the person's own home to make it possible to remain in the community.

Professionally managed service packages are at the other end of the consumer-direction continuum. Most publicly funded home- and community-based care programs, in which beneficiaries have access to a set of prescribed services, fall into this category. Typically, a professional care manager develops a care plan tailored to the needs of a particular client. Even within this approach, however, there is the potential for consumer direction. The extent of consumer direction is determined by the degree to which the client is proactive in the development and ongoing implementation of the care plan and has some control over other decisions related to service delivery.

Approaches reflecting increasing levels of consumer direction lie between these two extremes. Within some programs with service packages, clients have the discretion to hire and fire their own workers and to decide how and when services will be provided. Some programs allow individuals to hire family members as caregivers. Voucher programs fall short of allowing full client discretion through a true cash model, but within some constraints they do afford long-term-care consumers great flexibility in how and where benefits can be used.

To date, researchers and policy makers have considered consumer direction primarily within the context of homecare. In theory, the cash model provides the consumer with the discretion to purchase services in any setting. In reality, the amount of available dollars limits the purchase of facility-based care. At the same time, it would be a mistake to dismiss the potential of consumer direction in congregate settings. The underlying philosophy of assisted living, for example, requires that the resident have significant decision-making authority. Even in the nursing home, it is possible to provide residents with the opportunity to direct their care.

In defining consumer direction, it is important to note that this concept is related to but is not synonymous with consumer choice. With the advent of managed care and Medicare offering (at least in theory) a range of plans as well as a fee-for-service option, the elderly and younger disabled are facing more choices in how they receive their healthcare. Individuals also have choices in long-term care, although the costs of options such as assisted living or intensive homecare may limit accessibility for low- and moderate-income people and their families. Consumer direction, however, focuses more specifically on the degree to which people are proactive in making the decisions about care, including the hiring and firing of workers and the management and oversight of services. It is most appropriate for meeting nonmedical, personal care and other daily living needs that do not require the training, expertise, and judgment of professionals. Furthermore, because long-term care involves the quality of housing and other living arrangements as well as services, consumer direction has the potential for providing flexibility in the ways these needs can be met.

Policy Environment

Consumer-directed approaches to providing long-term care have gained prominence at both the federal and state levels over the past decade. There is, however, much ambivalence toward this concept, particularly the cash option and models that allow care recipients to pay family and friends as formal caregivers. Americans and their policy-making representatives in Washington and across the states embrace a consumer-directed approach when it is presented in the form of a tax deduction or credit for the purchase of private long-term-care insurance or a tax credit to the care recipient or informal caregiver for direct services purchased privately. Using private mechanisms such as the tax code puts dollars in the pockets of individuals and

their families and allows them to use broad discretion in how these funds are used. This private form of consumer direction resonates with the rugged individualism of American capitalism and the public's desire to make their own choices with minimal government interference.

On the other hand, when it comes to public programs and public dollars, there is evidence that the "deserving" and "undeserving" are treated differently. Policy makers, who ostensibly reflect the public's view, have no qualms about allowing individuals to exercise full discretion in how they purchase long-term care in the private sector. They are eager, in fact, to reward them through tax breaks and other financial incentives. The guardians of public long-term-care programs, however, are reluctant to offer consumer-directed options to low-income clients. There is tremendous concern about fraud and abuse, particularly where cash might be offered in lieu of a defined service package. It is assumed that at least a proportion of these individuals and their families would either use the funds for non-long-term-care purchases or would be incapable of making prudent decisions. Many policy makers also express grave concerns about paying family members for services that they should be providing for "free." In addition, much of the opposition to consumer direction emerges from concerns about lack of accountability and the inability to adequately protect long-term-care consumers from physical and emotional harm.

It is interesting to note that many Western European countries have pursued consumer-directed long-term care in the public sector through options ranging from caregiver and disability allowances to cash benefit programs based on social insurance. Concerns about fraud and abuse and accountability have not emerged as major deterrents to implementation in these other industrialized societies.

Despite serious reservation, many state policy-makers in the United States are finding consumer direction increasingly appealing for two reasons. First, there is the potential for cost savings. Most programs with a cash option, for example, discount the actual amount paid to the clients relative to the cost of a comparable service package. Savings are also realized through the reduction in administrative costs that would have been accrued in managing a service-package program. Policy makers are also interested in exploring consumer direction because of the growing shortage of frontline workers to deliver long-term care across all settings. Consumer-directed approaches afford much more flexibility in hiring workers (including relatives and friends), thus expanding the potential pool of caregivers. Finally, policy makers are interested in developing programs that address the preferences of their constituents. Consumer-directed long-term care is viewed as a way to empower consumers, affording them more choice and an increased role in making the decisions that directly affect them.

In This Issue

This issue of *Generations* provides a broad overview of consumer direction in long-term care, reflecting a range of perspectives from diverse stakeholders. Nancy Eustis sets the context for understanding the development of this approach by providing a brief history of this concept. She describes the evolution of consumer direction from its roots in the independent living and self-determination movements catalyzed by younger people with physical and developmental disabilities. She also highlights the ambivalence of the aging advocacy community toward this model but notes that elements of consumer direction have increasingly been present in aging services (e.g., control and autonomy, self-care).

Marshall Kapp notes that the current paradigm shift toward more consumer choice and control regarding the details of home health and personal assistance services implicates a variety of emerging legal issues. His article pays particular attention to the law's likely impact on quality assurance, consumers' rights, and workers' interests under long-term-care delivery and financing models that emphasize consumer direction. He argues that a movement away from extensive command and control regulation toward more emphasis on the role of consumer direction in a competitive long-term-care marketplace does not reduce the importance of the law in delineating and enforcing rights and responsibilities in this arena.

Pam Doty provides important insights into the federal policy perspective on consumer direction in long-term care. She uses her agency's leadership role in developing the Cash and Counseling Demonstration to illustrate how federal interest in this approach evolved over time and to identify some of the key barriers to adoption of this model. Linda Velgouse and Virginia Dize summarize the findings from their survey of state administrators on consumer-directed home- and community-based services. They also describe the development of a self-assessment tool by the National Association of State Units on Aging. As of this writing, ten states have volunteered to use this tool, which includes six broad categories of consumer direction "benchmarks."

Complementing this overview of state consumer-direction initiatives, Lori Simon-Rusinowitz and colleagues present findings from telephone interviews conducted with policy experts from the aging and disability communities. Kevin Mahoney, Kristin Simone, and Lori Simon-Rusinowitz highlight early implementation lessons from the Cash and Counseling Demonstration and Evaluation (CCDE), a multistate project funded by the Robert Wood Johnson Foundation and the U.S. Department of Health and Human Services. CCDE offers Medicaid Personal Assistance Services (PAS) users, elderly and younger people with disabilities, a cash allowance and support services as an alternative to traditional agency-delivered PAS services. As these researchers note, this large-scale demonstration provides a unique opportunity to assess the best approaches to developing an outreach and enrollment strategy, counseling and fiscal intermediary programs, and a system for quality monitoring.

Lynn Friss Feinberg and Claudia Ellano highlight California's Caregiver Resource Center as a model for promoting consumer direction in an agency-driven program for family caregiver support. They note that consumer direction poses challenges to traditional assumptions held by many practitioners who consider that professional intervention is not only appropriate, but required, based on the client's disability, age, or functional status.

Marisa Scala and Tom Nerney underscore the fact that it is people who are at the heart of the movements toward consumer direction and self-determination. These authors discuss four populations that have been involved in the struggle for consumer direction: older adults, younger adults with physical disabilities, people with developmental disabilities, and those with cognitive disabilities.

Mary Ann Wilner discusses the implications of consumer-direction for the frontline worker—the homecare aide or personal-care attendant who is employed directly by the consumer or the consumer's family. She outlines both the advantages and disadvantages of this model for the paraprofessional worker, including the opportunity for more autonomy and control, but also the potential for exploitation and abuse. In this article, Wilner describes the tensions between the needs and preferences of consumers and workers and reviews the role of mechanisms such as fiscal intermediaries, registries, unions, and public authorities in balancing the needs of the care recipient and the caregiver.

Scott Miyake Geron presents an approach to assuring quality of consumer-directed long-term-care programs that is based on the views of consumers and other consumer-derived quality measures as well as more traditional approaches. He discusses the failure of traditional approaches to assuring quality and notes that consumers define quality differently from professionals and other stakeholders. He also outlines the principal challenges to assuring quality.

Aging is a global phenomenon, and we have a lot to learn from the experiences of other countries that have implemented consumer-directed policies and programs to finance and deliver long-term care. Jane Tilly, Joshua Wiener, and Alison Cuellar analyze the experiences of Germany, Austria, the Netherlands, and France and compare them with selected U.S. programs in California, Colorado, Kansas, Maine, Michigan, Oregon, Washington, and Wisconsin. Based on interviews with researchers and key stakeholders in each country and state and an extensive review of the literature, these authors describe the range of program designs, highlight the experiences of beneficiaries, their family caregivers, and their workers, and review

emerging issues related to quality of services and the potential for cost containment.

To help readers understand the potential and pitfalls of consumer-directed long-term care in the real world, this issue showcases a number of programs that have implemented elements of this model. Ted Benjamin and Ruth Matthias briefly summarize findings from their study of California's In-Home Supportive Services program, which is large and well established and offers both agency and consumer-directed services. In the latter mode, the state delegates all responsibilities for recruiting, hiring, training, and supervising their worker to the client, with direct state payment to workers for certified hours of care delivered. Sue Flanagan and Pamela Green describe three fiscal intermediary models that are used to help facilitate consumer direction.

Diane Wong describes a rapid-response worker replacement program being implemented by the public authority operating in Alameda County, California. This function is key to enabling individuals to maintain their selected homecare workers and to avoid unnecessary 911 calls or institutionalization and escalating urgent situations. Kathy Dwyer describes the American Indian Choices Project, which is a self-directed method for developing aging program changes that are consistent with the Americans with Disabilities Act and that are respectful of tribal culture and sovereignty. Ruth Rothbart Mayer, Jean Marks, and Ann Berson describe a consumer-directed assistance program for people with cognitive impairment in New York City.

Conclusion

Consumer-direction in long-term care has become part of the lexicon among state and some federal policy-makers. This approach to financing and delivering long-term care was the focus of much attention at the most recent annual National Conference on Home and Community-Based Services. Policy makers, program directors, and researchers struggled with definitions of this concept and how it is being operationalized in programs serving a diversity of people with disabilities. They debated the advantages and disadvantages of this approach and articulated their concerns about consumer and worker protection, quality of care, and accountability. Clearly, consumer direction is not an option for all people with long-term-care needs, but it may prove to be an effective and efficient way to allocate precious resources to an important subset of this population. Although little empirical research has tested the perspectives of stakeholders who support or oppose this model, forthcoming findings from the Cash and Counseling Demonstration and other studies as well as the implementation experiences of ongoing programs may help guide the direction and magnitude of this emerging trend.